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Comment on: Wieser et al. Ovarian cancer in Switzerland: incidence and treatment according to hospital registry data. Swiss Med Wkly.2018;148:w14647

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Wieser and colleagues, in a study published in *Swiss Medical Weekly* in July 2018, compared incidence rates of ovarian cancer derived from the cantonal cancer registries (CCRs) as published by the National Institute for Cancer Epidemiology and Registration (NICER) with those derived from the hospital discharge data compiled by the Swiss Federal Statistical Office. The authors observed a substantial difference between these two estimates. The average age-adjusted ovarian cancer incidence rate was 14.6 per 100,000 women per year over the period 2004–2012 compared with a rate of 11.3 per 100,000 women per year reported by NICER for the same period [1]. The authors argue that the figure provided by NICER is probably an underestimation of the true figure because cancer registry data are based on voluntary information on new cases from clinicians. With our response, we show that this conclusion is not correct and the observed high rate of ovarian cancer in hospital discharge data is an artefact, probably arising from incorrect coding of non-malignant ovarian tumours. Further, we explain the purpose of epidemiological cancer registries and their difference from routinely collected discharge data.

Population-based (or epidemiological) cancer registries collect data from multiple sources on all new cancer cases occurring in a well-defined population, resident in a particular geographical region (e.g., canton). Their main objec-

tive is to produce statistics on the occurrence of cancer in a defined population and to provide a framework for assessing and controlling the impact of cancer in the community [2]. The key data sources are pathology laboratories, hospital records and death certificates, but also records from other facilities such as radiotherapy and oncology departments, imaging facilities and haematology laboratories, as well as hospital discharge data [3].

Epidemiological cancer registries were developed in Switzerland on a cantonal level starting the early 1970s, when the registries in Geneva, Vaud and Neuchâtel were established [4]. In the 1980s, the registries in Zurich, St Gallen and Basel followed. By now, all but two cantons register cancer cases and, according to the Federal Law on Cancer Registration (Bundesgesetz über die Registrierung von Krebserkrankungen (KRG); SR 9918.33), they also will start registration in 2020. In 2007, NICER was founded as a collaborative network to promote and support national population-based cancer registration and epidemiological cancer research in Switzerland. Since then, cantonal data have been combined to generate updated national cancer incidence and mortality statistics for public use [5].

Hospital discharge data are primarily collected and defined for administrative and reimbursement purposes [6]. Switzerland introduced the Swiss Diagnosis Related

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Groups (SwissDRG) on 1 January 2012 with the aim to promote cost containment, efficacy and transparency in hospital financing. Before that date, various reimbursement systems were applied depending on the canton [7].

Wieser et al. [1] argue that the incidence of ovarian cancer reported by NICER and the Swiss cantonal cancer registries is underestimated because registry data are based on voluntary information on new cases from clinicians. Based on our experience in cancer registration, we strongly believe that under-registration of cases is not the explanation for the observation made by Wieser et al. [1]. Completeness of case ascertainment is regularly checked regionally (by Swiss cancer registries), nationally (by NICER) and internationally (by the International Agency for Research in Cancer). In general, data quality indicators published by NICER and Cancer Incidence in Five Continents (C15) suggest completeness above international standard.

However, in order to evaluate further a potential systematic underestimation of cancer cases by the cantonal cancer registries, we compared incidence rates based on NICER data and on the hospital discharge data between 2011 and 2014. We selected two rare cancers with a high fatality rate very likely to be hospitalised (liver cancer [C22], pancreatic cancer [C25]) and three common cancers all likely to be hospitalised (intestinal cancer [C17-C21], breast cancer [C50] and lung cancer [C33/34]). Table 1 shows the age-standardised rates per 100,000.

For pancreatic cancer (men and women), lung cancer (men and women), intestinal cancer (men and women), and liver cancer (men), the age-specific rates for 2011–14 based on NICER data were 7.6% to 22% higher than rates based on hospital discharge data. Compared with NICER, incidence rates of breast cancer and liver cancer in women were higher based on hospital discharge data, although the relative difference is much smaller compared with ovarian cancer.

We evaluated in several registries how many cases received from the hospital discharge data turned out, after excluding prevalent and nonresident cases, not to be malignant ovarian cancer cases. After careful review of the pathology reports, 21–62% of all ovarian cancer cases reported by the hospital discharge data turned out to have a diagnosis of D39 (neoplasm of uncertain or unknown behaviour of female genital organs) or a completely different diagnosis. Although this is only evidence from some of the Swiss registries, the additional cases show a substantial proportion of misreporting on hospital discharge records. A study from Northern Ireland also reported a rather high proportion of wrongly coded ovarian cancer cases, leading to an overestimation of the incidence of ovarian cancer by hospital discharge data, though to a lower extent than in our comparison [8].

Our comparison of the two data sources does not show a general pattern of higher rates based on hospital discharge records. This argues against a systematic underreporting of cancer cases by data providers to the CCRs. Although it is true that in many cantons reporting of cases to the CCRs is or was not mandatory (e.g., in the canton of Zurich until 2016), almost all pathology institutes, hospitals and physicians participated in cancer registration. More importantly, underreporting, if based on non-reporting by certain hospitals, pathologists or physicians should not result in selective underreporting of one cancer site or in only one sex. In a previous evaluation of the completeness of case ascertainment in Swiss cancer registries [9], potential underregistration of ovarian cancer cases in the CCRs Basel and Zurich was observed. There is, however, no indication of substantial underregistration of ovarian cancer cases in Switzerland overall [9]. Notably, a recalculation of the average age-adjusted ovarian cancer incidence rate (2004–2012) excluding data from the CCRs Basel and Zurich remained comparable (11.9 per 100,000 women per year).

Importantly, hospital discharge data do not include information about the disease status of the patient (incident vs prevalent case). Wieser et al [1] addressed this issue by counting patients with a first ovarian cancer diagnosis as the main reason for hospital stay after an event-free period of six years and additional diagnoses in precedent hospitalisations of this individual. This approach might have two limitations. Firstly, it assumes high data quality before and after the introduction of SwissDRG (the analysis is mainly based on pre-SwissDRG data). To the best of our knowledge, no data quality report on Swiss hospital discharge data is publicly available. However, experiences from other countries give rise to doubts concerning the pre-SwissDRG period [10]. Secondly, malignant neoplasms may be detected during a hospital stay due to another health problem (and therefore mentioned only as additional diagnoses), and the first hospitalisation with this cancer as main diagnosis, hence, may occur only few weeks or months later.

In conclusion, we can rule out a systematic underregistration of ovarian cancer in the CCRs. Furthermore, there is support for the notion of misclassification of ovarian cancer in Swiss hospitals.

For a valid judgement, a thorough case-to-case alignment of hospital in-patients with an ovarian cancer diagnosis and their capture during cancer registration would be needed. However, with its systematic data collection using multiple sources and established regular quality control according to internationally valid standards, cancer registration as performed by the CCRs in Switzerland still provides the most reliable cancer incidence data in Switzerland.

Table 1: Age-standardised incidence rates* of selected cancer sites for the period 2011–2014 according to hospital discharge data and NICER data, with their relative difference.

	Hospital discharge data ("Wieser" method)		NICER		Relative difference	
	Male	Female	Male	Female	Male	Female
Ovary		14.2		10.6		–34.0%
Breast		119.2		111.7		–6.7%
Pancreas	11.0	8.9	12.4	9.8	+11.3%	+9.2%
Lung	38.7	24.0	49.6	28.4	+22.0%	+15.5%
Intestine	45.6	31.5	49.8	34.1	+8.4%	+7.6%
Liver	10.3	3.8	11.6	3.4	+11.2%	–11.8%

NICER = Swiss National Institute for Cancer Epidemiology and Registration * Average rates computed from the rates per year using the European Standard population (1976)

Disclosure statement

MA and IC head the Cancer Registry Aargau. MCM is head of the Cancer Registry of Cantons Neuchâtel and Jura. DD is a scientist of the Cancer Registry of Central Switzerland. YB is manager of the Cancer Registry of Fribourg. AB is director of Ticino Cancer Registry. JLB is the scientific head of the Vaud and Neuchâtel-Jura Cancer Registries. JD is head of the Cancer Registry of Central Switzerland. AF and ML are employed by the National Institute for Cancer Epidemiology (NICER). IK is head of the Valais Cancer Registry. MM is the director of the East Switzerland Cancer Registry and the medical director of Cancer Registry Graubünden and Glarus. ER is the director of the Geneva Cancer Registry. SR is head of the Cancer Registry of the Cantons Zurich and Zug. KS is the head of the Basel Cancer Registry. UW is the director of the National Institute for Cancer Epidemiology (NICER)

References

- 1 Wieser S, Schmidt M, Kind AB, Heinzelmann-Schwarz VA. Ovarian cancer in Switzerland: incidence and treatment according to hospital registry data. *Swiss Med Wkly.* 2018;148:. doi: <http://dx.doi.org/10.4414/smwm.2018.14647>. *PubMed*.
- 2 dos Santos Silva I. *Cancer epidemiology: principles and methods.* Lyon, France: International Agency for Research on Cancer (IARC); 1999.
- 3 Bray F, Ferlay J, Laversanne M, Brewster DH, Gombe Mbalawa C, Kohler B, et al. Cancer Incidence in Five Continents: Inclusion criteria, highlights from Volume X and the global status of cancer registration. *Int J Cancer.* 2015;137(9):2060–71. doi: <http://dx.doi.org/10.1002/ijc.29670>. *PubMed*.
- 4 Arndt V. Population-based cancer registration and research in Switzerland: examples, limitations and perspectives. *Swiss Cancer Bulletin.* 2016;36(2):163–7.
- 5 Clough-Gorr K, Bosshard D, Heusser R, Nosedà G. The Potential Benefits for Cancer Prevention and Control in Switzerland from a New National Cancer Registration Law. *Swiss Cancer Bulletin.* 2011;31(2):154–5.
- 6 Maier B, Wagner K, Behrens S, Bruch L, Busse R, Schmidt D, et al. Comparing routine administrative data with registry data for assessing quality of hospital care in patients with myocardial infarction using deterministic record linkage. *BMC Health Serv Res.* 2016;16(1):605. doi: <http://dx.doi.org/10.1186/s12913-016-1840-5>. *PubMed*.
- 7 Thommen D, Weissenberger N, Schuetz P, Mueller B, Reemts C, Holler T, et al. Head-to-head comparison of length of stay, patients' outcome and satisfaction in Switzerland before and after SwissDRG-Implementation in 2012 in 2012: an observational study in two tertiary university centers. *Swiss Med Wkly.* 2014;144:. doi: <http://dx.doi.org/10.4414/smwm.2014.13972>. *PubMed*.
- 8 Middleton RJ, Gavin AT, Reid JS, O'Reilly D. Accuracy of hospital discharge data for cancer registration and epidemiological research in Northern Ireland. *Cancer Causes Control.* 2000;11(10):899–905. doi: <http://dx.doi.org/10.1023/A:1026543100223>. *PubMed*.
- 9 Lorez M, Bordoni A, Bouchardy C, Bulliard JL, Cerny B, Dehler S, et al. Evaluation of completeness of case ascertainment in Swiss cancer registration. *Eur J Cancer Prev.* 2017;26:S139–46. doi: <http://dx.doi.org/10.1097/CEJ.0000000000000380>. *PubMed*.
- 10 Burns EM, Rigby E, Mamidanna R, Bottle A, Aylin P, Ziprin P, et al. Systematic review of discharge coding accuracy. *J Public Health (Oxf).* 2012;34(1):138–48. doi: <http://dx.doi.org/10.1093/pubmed/fdr054>. *PubMed*.